

Portrait of an Artist: A Final Study

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ABSTRACT

The life of an accomplished, independent 53-year-old woman is completely changed after surgery for a large, invasive spinal cord tumor. A lengthy, unsuccessful attempt at recovery and rehabilitation, compromised by multiple complications and hospitalizations, led to the patient's choice to come off the ventilator. Her end-of-life decision allowed her to die peacefully, surrounded by family and friends, all of whom were profoundly affected by the experience.

In 2005, my 53-year-old sister lived in New York City working as a book designer for a large publishing house. Divorced for more than 20 years, she had adapted to life in the big city. Although independent and resourceful, she had a close circle of friends in both New York and our hometown of Toledo, Ohio. She usually devoted her vacations to visiting my parents even though I know other travel destinations were on her wish list.

J, as I'll refer to her, was the second daughter of four. When we were young girls, I remember J creatively altering the faces of her dolls and constructing various objects with scrap lumber and nails in our garage. Her creative bent and talents had an impact on the course of her education, and she earned two master of fine arts degrees, one in printmaking and a second in graphic design.

For approximately 1 year, J had experienced mild to moderate neck pain that progressed to a tingling sensation in her hands and some loss of balance. Treatment with outpatient physical therapy failed to alleviate the symptoms, so her physicians scheduled a computed tomography (CT) scan. The terrifying

results of that scan initiated a journey of treatment and attempted recovery that began in New Orleans and finally ended in Toledo.

Magnetic resonance imaging (MRI) to confirm and expand on the results of the CT scan revealed a very large spinal cord tumor that filled the foramen magnum and descended to C6. Surgical removal of the tumor was obviously a complicated and risky procedure portending a lengthy postoperative recovery. Because she lived alone in New York, J chose a hospital in a city with family nearby and came to Ochsner in June 2005 for her surgery.

The tumor was extensive, highly vascular, and entwined around cranial nerves. Although resection was performed as carefully as possible, the neurological damage was significant. Following an arduous 17-hour operation, J had a prolonged assisted ventilation recovery in the intensive care unit (ICU). Unfortunately, she was still in the ICU on August 29th when the emergency generators failed after Katrina. She was forced to leave in those first terrible days after the storm with other respirator-dependent patients and evacuated to Houston.

Her journey after Katrina continued 2 weeks later with a chartered medical flight from Houston to a hospital in Toledo. Because of some medical care issues, she was then transferred to a medical center in Detroit. She had left-sided hemiplegia and the physical problems of a high quadriplegic. The list of complications included left-sided paralysis affecting the diaphragm, neurogenic bladder, double vision, and ventricular enlargement requiring a ventriculoperitoneal shunt. She was respirator dependent for more than a year, with a tracheotomy left in place for almost 3 years.

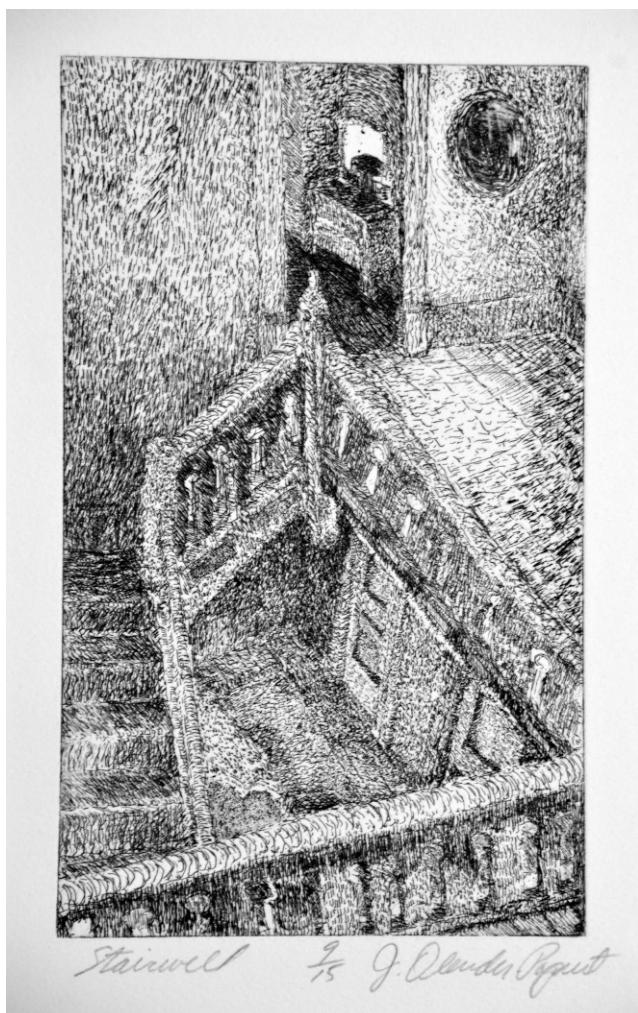
She was transferred from the acute care hospital in Detroit to a long-term acute care (LTAC) facility, then to a rehabilitation facility before moving in with one of our sisters, where she stayed for a year. The remaining years of her life involved multiple medical crises and hospital admissions. J spent time in LTACs, rehabilitation hospitals, and acute care facilities. For 2 years prior to her death, she lived with my elderly father in his home. Both required care and assistance on a daily basis from paid helpers as well as my two sisters in Toledo but lived as independently as possible.

I went to Ohio several times a year to stay with my father and J, sharing oversight of their care with my

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sisters. During the first year they lived together, J managed well within the limits of her disability. She paid the helpers, prepared grocery lists, made appointments for both her and my father, and cooked dinner almost every night. She spent most of her day in a wheelchair and used a walker to exercise in the house. Her pulmonologist reluctantly agreed to remove her tracheotomy tube on the condition she wear a mask overnight to control sleep apnea.

During the last year of her life, J demonstrated a gradual deterioration of both her physical and mental status. Eating became an arduous task, and her weight fell precipitously. Skin problems developed, and a bedsore formed over her coccyx. She often burned her right hand and arm when cooking. J often neglected to wear her mask at night, with resulting hypoxia that made her increasingly lethargic. She fell asleep sitting in her wheelchair and either slid to the floor or, worse, hit her head as she fell. Remembering to pay bills and schedule appointments became a problem, and life was less well organized in the house.

J adamantly expressed her opposition to another hospital admission for any reason. However, on a

Sunday morning in late March 2010, my father and the helper were unable to awaken her. They finally called 911, and J left the house for the final time.

Evaluation of her condition revealed that her shunt was blocked. Surgery required to regulate the shunt resulted in respiratory insufficiency and a tracheotomy. When they could not wean J off the respirator, she was transferred to an LTAC facility.

Unfortunately, she failed to improve. She could not tolerate time off the ventilator, and abdominal distension from paralytic ileus made her too nauseated to take anything by mouth. J had decided that she was finished fighting for recovery. Another prolonged period of ventilation could not be tolerated, and she did not see the quality of her life improving. The hospital offered hospice care, and J moved into that part of the facility. She was cognizant of her deteriorating physical status and had signed a do not resuscitate form.

Family and friends began to gather for the final vigil. Although the staff kept her medicated for abdominal pain, J somehow managed to stay awake whenever anyone was in the room. Because of the tracheotomy, she could not speak but smiled and nodded as we conversed and reminisced. One of my sisters brought in family photo albums with photographs from childhood to adulthood. We put favorite images on the wall at the foot of the bed so she could see them at all times.

When J lived with my sister in Toledo, my sister's dog Jack devoted himself to J. The hospital allowed my sister to bring Jack to the room, and he jumped on the bed, curled up next to J, and licked her hand until it was time to go home.

After consulting with the hospital staff, J chose April 12, 2010, as the day to come off the respirator and end her ordeal. J seemed prepared and at peace. We also had prepared ourselves as well as possible for that morning. In a very professional and caring manner, the staff provided support and privacy, limiting the frequency of times they came into the room. We all said our last goodbyes before a clinical nurse specialist administered a high level of sedation and disconnected the vent. As we watched and cried and my father held her hand, J died peacefully in only 20 minutes.

J had arranged to donate her remains to the local medical school. A month later, family and friends gathered to celebrate her memory in a reception hall at a church in Toledo where my father and youngest sister are members. At the front of the room were tables laden with food and beverages. The remaining three walls were lined with tables covered with portfolios filled with J's etchings, prints, and copies of the many books she had designed. Guests were

encouraged to take both artwork and books as remembrances.

As I wrote this narrative, I had to stop frequently and let waves of emotion pass so I could continue the story. The nurse who assisted J the day she died said

she felt it was a privilege to be part of J's end-of-life experience. I believe that was true for all of us who were present in her room that day. J managed to keep her dignity and to remain in control of her destiny. She is always in my thoughts.